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ABSTRACT

The parent of a handicapped child reviews the development of parent groups and parent advocacy internationally. Among the programs described are weekend education courses for parents in Norway, deinstitutionalization efforts in England, mass media approaches in France, and the Extend-a-Family program in Canada in which a handicapped child is matched to a volunteer family. Concerns are voiced about the availability of early infant intervention programs, the need for deinstitutionalization, and the importance of respite care. The similarity of parents' needs throughout the world is stressed. (CL)

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INTERNATIONAL TRENDS IN THE PARENT MOVEMENT: OBSTACLES AND OPPORTUNITIES

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I am happy to share with you my perspective of the development of parent groups and parent advocacy that is occurring internationally. As the parent of a handicapped child, this is a terrific opportunity to communicate the advances in this field. In order to adequately describe my experiences both in reviewing programs and in getting to know parents in many places, first I need to share some of the personal events in my life and, secondly, to share the professional opportunities that I have experienced. These events were the "growing ground" for me to walk on and through to prepare me to appreciate many of the mutual exchanges of information with parents of handicapped children that I've had.

I would like to begin by telling you my personal experiences with my 7th child, Jane, my 9-year-old daughter. Jane's birth was what I consider to be a perfect, unmedicated, spontaneous birth. All was well. However, within her first two months, I noticed differences, by six months I was alarmed. The searching and questioning which caused such frustration and anger continued until she was 14 months of age. Another new doctor at this time very calmly told me "It is simple, your daughter is mentally retarded." He then recommended that I take her home and keep her comfortable for a couple of years. Fortunately for Jane and her very distressed family, during the next days and weeks, three parents of mentally retarded children contacted me and encouraged me to seek help for her. Each parent shared his/her experience, strength and hope with me, thus giving me a beginning. Shortly, I went to the diagnostic center that the parents had recommended and to which the doctor had refused to make a referral. That same center is the Meyer Children's Rehabilitation Institute where I am now employed! From that day to this, Jane and her whole family have been helped by many innovative programs and through the efforts of many parents and professionals.

The early help and intervention that I received for my daughter was a foundation for me when in 1974 I became the Coordinator of the Pilot Parent Program of the Greater Omaha Association for Retarded Citizens (GOARC). This is a program in which parents of handicapped children help parents who have recently learned that their child is handicapped. Trained parents offer emotional support, factual information, introduction to helpful persons and groups, and any other assistance to aid the parent in crisis. During my five years in Pilot Parents, I served as a local, state, and regional coordinator. The most recent work involved establishing 35 new Pilot Parent Programs in four states--Kansas, Nebraska, Iowa and Missouri.

With this background, I sought and received a Rosemary F. Dybwad International Award which enabled me to interact in a mutual sharing of family advocacy groups in France, England and Norway. After receiving the award, the Canadian Association for Mental Retardation invited me to add their country's programs to my itinerary. This paper will address my observations of what is occurring in these countries as well as our own on behalf of parents of handicapped children.

To begin with, I will make some general observations of this tour. There is an international family of those with family members who happen to be mentally retarded. I was "at home" in so many far away places because of the bond of our common experiences and goals. I have interviewed parents everywhere who are aware of the important role they hold. They are committed to change. They are searching, struggling, and experiencing with the principles of normalization. The awareness of their person's rights are evident and pressing. The people I met know that there is strength in numbers and that laws must respond to people's needs. To my great fortune, the leaders I met were most definitely leaders! And one thing that impressed me so strongly about all the places that I went was the people. In every instance, where I found good and even great things happening, there was a person who was a spark plug--a catalyst. Even when the facilities weren't grand, the funding shaky, or the geographical setting difficult, it was the people who were making the difference. In many instances, small amounts of funding are used to get large amounts of work done in parents' hands.

Let me tell you about some of these people and what they are doing--

In Norway--Vigdis Øiann is the leader of the national system of the Courses. This is a part-time activity for this English teacher. With the assistance of her husband Henri, local coordinators, and many volunteers, the National Association in Norway offers many such weekend Courses for parents, families and siblings in their country.

I participated in the second such week-end Course for families at Tussegrend, a camp located two hours from Trondheim, Norway. Twenty-five families came together for education, fun, sharing, and caring. There were two lectures followed by small groups and an update on all local activities. The remainder of the week-end was comprised of numerous family experiences. There was a fishing trip in the Trondheim fjord, a huge bonfire, a dance, and many individual and group opportunities.

The Norwegian government with the activism of the National Association funds these weekends. The majority of the Courses are for parents. The same format that occurred in the family course is employed on parent weekends--education, rest, relaxation, sharing and caring. Also, there have been a couple of sibling courses following this outline.

The National Association in Norway spent the first ten years of formation using the course approach. At its 10th year anniversary in 1978, there were over 10,000 members.

Frambu was an unexpected stop in Norway. This center, designed for polio treatment, is an adapted teaching center for parents and handicapped persons. Again, the part-time leaders that I met, both mothers of mentally retarded children, were so charismatic. They had a special way of assisting the 15 families to experience every combination of learning possible.

The leaders and whole families stayed at Frambu 14 days for intensive care, learning, rest, and relaxation. During that two weeks, every possible subject relating to having a handicapped family member, as it relates to every family member, was covered. Again this opportunity was funded through the efforts of the Norwegian government. The child care component of Frambu was a training program for staff.

In England--Alan Kendall, the director of the Northwest Division of Dr. Barnados, provides many services for retarded children in the Liverpool, Chorley area of England. Under Alan's inspirational direction are some very key people. Liz Dodson coordinates the foster and adoption scheme for difficult-to-place children. Marian Bacal, Mildred Austin and Linda Nolan, of the Chorley toy library, are a trio of dynamic personalities. Their response to family needs is to do whatever is needed. To that end they provide play groups, a Plus Two program, a fathers' rap group (this was the only group that I encountered just for dads), and a summer respite-play scheme. Plus Two is a simple recruitment of local people who are willing to help families with retarded children. The respite play scheme is provided during the summer break. It is a two-day per week respite opportunity for handicapped children operated by a volunteer staff. The staff from the toy library serves as a catalyst for this operation.

John Axten at Barrows Green also provides exemplary leadership. At this facility, 8 beds are residential care units and 8 beds are for respite holiday care. Barrows Green is located in the beautiful rolling hills of England. The

permanent staff has a very low turnover rate. This beautiful respite care facility is booked for holidays through 1981 as it is in so much demand.

Christine Washington directs the core of residential units in Skermsdale in the Barnado system. This system of alternative living units provides a one:two opportunity for maximum growth and development of each client. The children fondly addressed the staff as "auntie" and "uncle" which reflects the warmth and closeness of the environment. Here I met 15-year-old Tony who recounted to me the names and homelands of many of the foreign visitors he has met.

In the Rotherham-Sheffield area of England, I met Dr. Hugh Firth and Dr. Mary Myers, a psychiatrist. These parents are advocates in the forefront of deinstitutionalization and community service provision. The outstanding community support programs were mums and baby groups (the outreach from this group to newly identified families occurred within 12 hours after notification); parent training programs, a one-year identification program to reach every mentally handicapped person/family in the region through personal interview and planning effort. The deinstitutionalization efforts provided were: (1) a day program for severely involved citizens who prior to this had no alternative for care except the institution, (2) an intensive care unit for severely medically involved children, (3) a respite care unit for the clients who had returned home, (4) training programs for parents working with their sons and daughters who had come home from the institution or who resided at home, (5) a system of group homes for those who require residential care outside their natural homes. In meeting many of the parents, it was so refreshing to see them so happy about having their son or daughter returned home. These parents are very involved in the care, plan and placement of their children. Most of these clients are in their late teens or young adulthood.

My next stop in England was at Honeylands in Exeter. This huge Georgian mansion houses a terrific resource/respite care facility for children and families. The parents, Chris Markham and Rosemary Huxtable, said it best. They quoted staff as telling the parents, "You (parents) are the experts, we are the professionals." They describe this 24-hour 365-day per year respite center as "Honeylands is my Bible. It is the only professional body that says to a parent 'What do you need?' 'What do you want to help you with your child?'" Honeylands offers parent relief as a major goal. Included in the services are babysitting, play groups, overnight stays, weekend and holiday stays, nursery

groups, individual or group therapy, parent education, peer therapy, and specific therapies for the child. It is noteworthy that no child has been institutionalized from the Exeter area of England in five years.

In France--the parent movement displays strength and viability at all levels. In Paris, from the national headquarters to the local group in Antibe, I saw parent leaders in a highly structured yet simply delivered system. Locally, in Paris, I encountered Louise Bethmont, a parent advocate and teacher through the local association. As parents seek information about the national association or the services through the local affiliate (the two offices are in the same building,) Louise is the first person encountered. She has developed a sensitive and understanding approach to new parents. Her goal is to refer new parents to all people and programs necessary.

From the national association I discovered a mass media approach. Publications and publicity about mental handicaps are underway. The national work done by this group in the education of physicians is interesting. An information book by physicians for physicians is distributed to 60,000 physicians in France. Dr. Paul Bierant is the physician/father of a handicapped daughter who worked diligently to see this work produced. He and his wife Marcel have been active in providing help to families of mentally retarded children. While they lived in Tunisia, they spearheaded all services and assistance to families there. Later, from their Parisian home, they assisted any family of a mentally retarded child living in a French protectorate. Among the parents that I encountered, Dr. and Madam Bierant touched me deeply. Their retarded daughter died accidentally 20 years ago, yet their continuing commitment to the ideals of service are ever present.

Madam Noelle Bompar was my hostess for the visit to Marseille, Antibe, and Nice. Madam Bompar, a national, regional and local leader, has such charismatic qualities. Her exhortations to parents and their response reflected an almost "religious" commitment to their collective goals.

The city of Marseille is divided into 16 sections. A parent leader, with the help of volunteer assistants, provides supportive services to any parent within his/her section. The educational/vocational/residential services are provided locally with the support of the national association. There is emphasis on quality educational schooling along with recreational/sport programs for their

students. Some of the sporting activities were "super"--highly developed swimming programs, overnights in the mountains, and boating outings to the nearby islands.

The parents' programs in the region of Southern France have systems to advertise their association. To that end, there is publicity in every weekly newspaper notifying the readership of available help along with meeting notices and other publicity. Posters describing parent assistance delivered publicly a few hours a week are reminders of the help available. This group of parents, with their support to one another and their outreach activities, reminded me of the Pilot Parents back home.

In Canada--the Pilot Parent Programs were the first that I reviewed. Fran Porter, a co-founder of the Pilot Parent Program and a Canadian herself, introduced the concept of Pilot Parents. How exciting it was to meet parents following the Omaha program of a system of services that can reach so many parents. Toronto is so large that it is divided into four segments for services of Pilot Parents. On my return trip from Europe, one Pilot Parent leader, Kinga de Munich, traveled 8 hours to and from London, Ontario to experience our mutual parent information exchange.

The Extend-a-Family is one of the most innovative programs that I reviewed. The leadership of this organization, comprised of both parents with and without handicapped children, provided me with valuable information on the subject of normalization. The teachers exhibited an urgent demand that mentally retarded children have an integrated "other" home and family. This is their Extend-a-Family. This highly developed system matches the handicapped child with a family who has been recruited to become an integral part of that child's life. The host home responds to whatever needs are identified by the parents and child. The parents pay a set fee for the hours that their child spends at the Extend-a-Family.

Meeting Jo Dickey, the President of the Canadian Association for the Mentally Retarded and a parent of a handicapped son, was an interesting opportunity. We met at midnight in a Toronto hotel as I had just arrived from Europe and she was leaving soon for Vancouver. Jo has been instrumental in the development of the Woodlaws parent group. This group of parents, whose sons and daughters reside in institutions, provides support to its members in support of deinstitutionalization. These parents are not only committed to the fact that they want deinstitutionalization for their children, but they are also willing to work

toward developing the services needed to facilitate this process. They are extremely intent on the idea that the fixed point of responsibility, such an intense need for parents, be transferred from institutional personnel to community-based leaders. In Canada this fixed point of responsibility is in the Community Living Board (CLB). A representative of the CLB, a trained parent advocate, and the parent of the handicapped person form a triad to plan and implement community placement. By including families in the planning process from the very beginning, along with strong emotional support from the parent advocate, successful placements are occurring.

A program of home intervention is operated by the Metropolitan Toronto Association for Mentally Retarded (MTAMR). Accompanying Bobbi Steinman, the staff person from MTAMR, during a visit to the home of a severely involved girl exemplified how this program works. This bright eyed, Asian child reflects the efforts of her parents, extended family and Bobbi Steinman. Responding to parental request assistance, this program provides one-on-one precision teaching methods for parents to remediate difficult behaviors and to teach needed skills for their handicapped child. This intervention service is widely used in the Toronto area.

In the United States--I have had the privilege of interacting with many parents. Noted in the beginning of this paper is my involvement in the Pilot Parent Program and many programs of similar concept. Direct replications of the Pilot Parent Program exist from Florida to Arizona and from Illinois to Alaska. Some advances that I see in our parents are (1) the recognition of their collective and individual strengths, (2) a renewed emphasis on parental involvement, (3) the mutual growth in parents as a result of parent support services, (4) the commitment of parents to normalization as demonstrated in the demand for integrative services along with supportive mainstreaming principles, (5) the awakening of the rights of handicapped persons acknowledged by parents in demanding services as a right, (6) the acceptance of and demand for in-home support and training services which reduce the incidence of institutionalization, (7) the recognition by professionals of the importance of individual parental involvement along with the recognition that parents have a different service to render to one another.

By contrast, I could list for you the negative side of each one of the aforementioned positive observations. How ever, this would not benefit this

report. The greatest needs I see in service provision for parents in the United States are trained parent-to-parent services for parents at every age and stage. This would provide parental help for parents of young children, adolescent children and adult children. For parents of adults there is a two-fold need for parents whose adult sons or daughters are at home, and assistance for parents whose children are institutionalized. The tremendous need for the latter is escalated if the son or daughter is being returned to the community.

Some conclusions--so many of the programs that I've described are excellent. But I need to note that in almost every instance, the provision of service barely scratches the surface of need. And almost all of the parent leaders and advocates that I've talked to realize this. They are a committed lot. The task of educating, supporting and strengthening parents and families is an enormous one. And yet, everywhere I went, parents are striving to further the opportunities for their children, and indeed, all handicapped children. Some observations I've made about areas of need--in Norway, parents are working diligently to reduce the unspoken resistance between parents and professionals. This same attitude is prevalent in France. In both countries the leadership is aware of these prejudices and working to reduce them.

I was concerned in England, France and Norway as to the availability of early infant intervention programs for handicapped children. An outstanding program of identification of infant needs is the Save-the-Baby campaign in England. This is a national program of the Spastic Society which identifies infants who are developmentally delayed.

In all the countries, the need for deinstitutionalization is still prevalent. There are good examples everywhere of programs designed to reduce the incidence of institutionalization and efforts to return people to their communities.

In the European countries, I observed a much greater emphasis on respite care for holiday times. This is a cultural difference and also I think a beginning step to a fuller array of services in these countries.

The Canadians demonstrated leadership in expanding voluntary services to include many Canadian citizens currently uninvolved with handicapped persons.

Some final observations--

- Parents are so similar everywhere.
- Parents want to keep their children in their own homes until appropriate separation times. Parents' value systems are challenged by having a handicapped child. The acceptance of the child realigns values in a spiritual sense.

- Parent needs are culturally and geographically influenced but very similar.
- Parents' needs for future security of their child is universal.
- Parents everywhere demonstrated the ability to care for each other and to truly help one another.
- Parents need to be able to work in partnership with professionals, and vice versa.